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Social and human rights questions: genetic privacy and non-discrimination

Chile: revised draft resolution

Genetic privacy and non-discrimination

The Economic and Social Council,

Guided by the purposes and principles set forth in the Charter of the United Nations and also by the Universal Declaration of Human Rights,[1] the International Covenants on Human Rights[2] and the other relevant international human rights instruments,

Recalling the Universal Declaration on the Human Genome and Human Rights adopted on 11 November 1997 by the General Conference of the United Nations Educational, Scientific and Cultural Organization[3] and to General Assembly resolution 53/152 of 9 December 1998 endorsing the Declaration,

Recalling also the Programme of Action of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, adopted in Durban, South Africa, on 8 September 2001,[4]

Welcoming the International Declaration on Human Genetic Data adopted on 16 October 2003 by the General Conference of the United Nations Educational, Scientific and Cultural Organization, which, inter alia, considers discrimination based on genetic characteristics as acts intended to infringe, or to have the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to stigmatization of an individual, a family or a group or communities,

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[1] General Assembly resolution 217 A (III).
[2] General Assembly resolution 2200 A (XXI), annex.
[3] United Nations Educational, Scientific and Cultural Organization, *Records of the General Conference, Twenty-ninth Session*, vol. 1, *Resolutions*, resolution 16.
[4] See A/CONF.189/12 and Corr.1, chap. I.

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Recalling its resolution 2001/39 of 26 July 2001,[5] as well as its decision 2003/232,[6]

Recalling also Commission on Human Rights resolution 2003/69 of 25 April 2003 on the question of human rights and bioethics,[7]

Recalling further the decision taken on 7 May 1998 whereby the Executive Board of the United Nations Educational, Scientific and Cultural Organization established the International Bioethics Committee, which is carrying out work on confidentiality and genetic data,

Reiterating that the life and health of individuals are inevitably related to developments in life sciences and social areas,

Acknowledging the importance of advances in genetic research, which have led to the identification of strategies for early detection, prevention and treatment of diseases,

Bearing in mind that the genetic revolution has far-reaching implications and consequences for all humankind, and that its evaluation and applications should thus be conducted in an open, ethical and participatory manner,

Recognizing the contribution that civil society involved in this matter can make to the protection of genetic privacy and to the fight against discrimination based on genetic information,

Reaffirming that the information obtained from genetic tests, which is personal, should be held confidential, based on the conditions set by law,

Recognizing that genetic data associated with an identifiable person can in some instances be relevant to other members of the individual's family or to other persons and that the rights and interests of such persons must also be taken into account in the handling of such data,

Stressing the fact that revealing genetic information belonging to individuals without their consent may cause harm and discrimination against them in such areas as employment, insurance, education and other areas of social life,

Recalling that, in order to protect human rights and fundamental freedoms, the limitations to the principles of consent and confidentiality may be prescribed only by law, for compelling reasons consistent with international law, including international human rights law,

1. *Takes note* of the reports of the Secretary-General on information and of the comments received from Governments and relevant international organizations and functional commissions pursuant to Economic and Social Council resolution 2001/39;[8]

2. *Expresses its appreciation* to the Governments, relevant international organizations and functional commissions that have responded to the request for information formulated by the Council in its resolution 2001/39;

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[5] See *Official Records of the Economic and Social Council, 2001, Supplement No. 1* (E/2001/99).

[6] See *Official Records of the Economic and Social Council, 2003, Supplement No. 1* (E/2003/99).

[7] *Official Records of the Economic and Social Council, 2003, Supplement No. 3* (E/2003/23), chap. II, sect. A.

[8] E/2001/91 and Add.1 and E/2004/56.

3. *Urges* States to ensure that no one shall be subjected to discrimination based on genetic information;

4. *Also urges* States to protect the privacy of those subject to genetic testing and to ensure that genetic testing and the subsequent processing, use and storage of human genetic data is done with the prior, free, informed and express consent of the individual or authorization obtained in the manner prescribed by law consistent with international law, including international human rights law, and to ensure that limitations on the principle of consent be prescribed only for compelling reasons such as forensic medicine and related legal proceedings, by domestic law consistent with international law, including international human rights law;

5. *Calls upon* States to take appropriate specific measures, including through legislation, to prevent the misuse of genetic information leading to discrimination against, or stigmatization of, individuals, members of their families or groups in all areas, particularly in insurance, employment, education and other areas of social life, whether in the public or the private sector, and in this respect calls upon States to take all appropriate measures to ensure that the results and interpretations of population-based genetic studies are not used for purposes that discriminate against the individual or group concerned;

6. *Also calls upon* States to promote, as appropriate, the development and implementation of standards providing appropriate protection with regard to the collection, storage, disclosure and use of genetic information taken from genetic tests that might lead to discrimination, stigmatization or invasion of privacy;

7. *Urges* States to continue to support research in the area of human genetics, subject to accepted scientific and ethical standards and to the potential benefit of all people, emphasizing that such research and its applications should fully respect human rights, fundamental freedoms and human dignity, as well as the prohibition of all forms of discrimination based on genetic characteristics;

8. *Recognizes*, in this context, that international efforts to ensure non-discrimination on genetic grounds need to be pursued and that, in the context of international cooperation, States should endeavour to assist developing countries to build their capacity to participate in generating and sharing scientific knowledge concerning human genetic data and the related know-how, with full respect for all human rights;

9. *Decides* to continue considering the various implications of the question of genetic privacy and non-discrimination for ethical, legal, medical, employment, insurance-related and other aspects of social life, consistent with public international law and the international human rights law;

10. *Requests* the Secretary-General to bring the present resolution to the attention of all Governments, relevant international organizations and functional commissions, to collect comments received pursuant to it, and other relevant information, and to submit a report to the Council at its substantive session of 2007.